

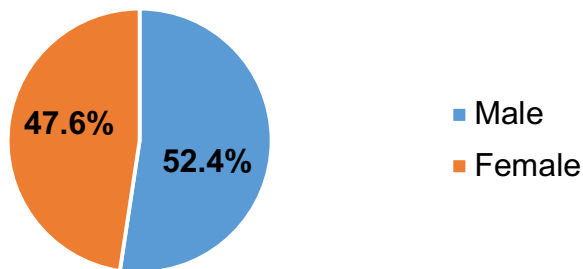
BABIES COUNT

The National Registry for Young Children with Visual Impairments (aged birth to 36 months)

First Year Results: March 2016 to June 2017
Overall sample of 588 children

Child Characteristics:

Gender

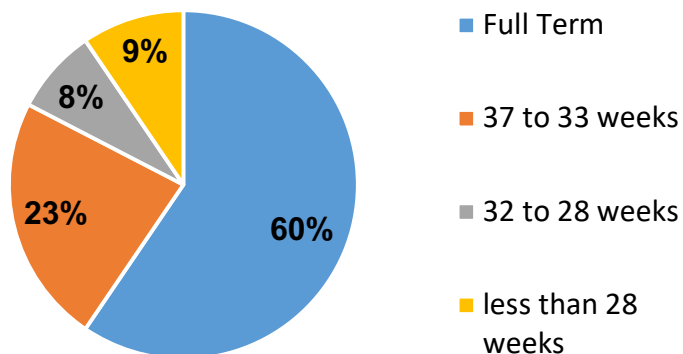


Male = 308
Female = 280
Total = 588

Birth weight

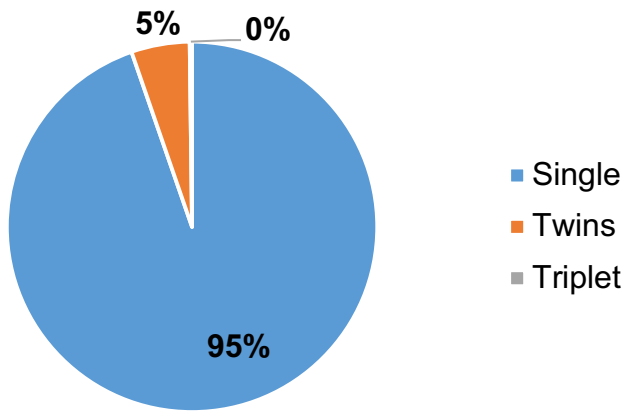
- Average weight = 5.98 lbs
- Smallest = 1.1lbs
- Largest = 15.2lbs
- Sample = 499
- Missing/unreported = 89

Gestational age at birth



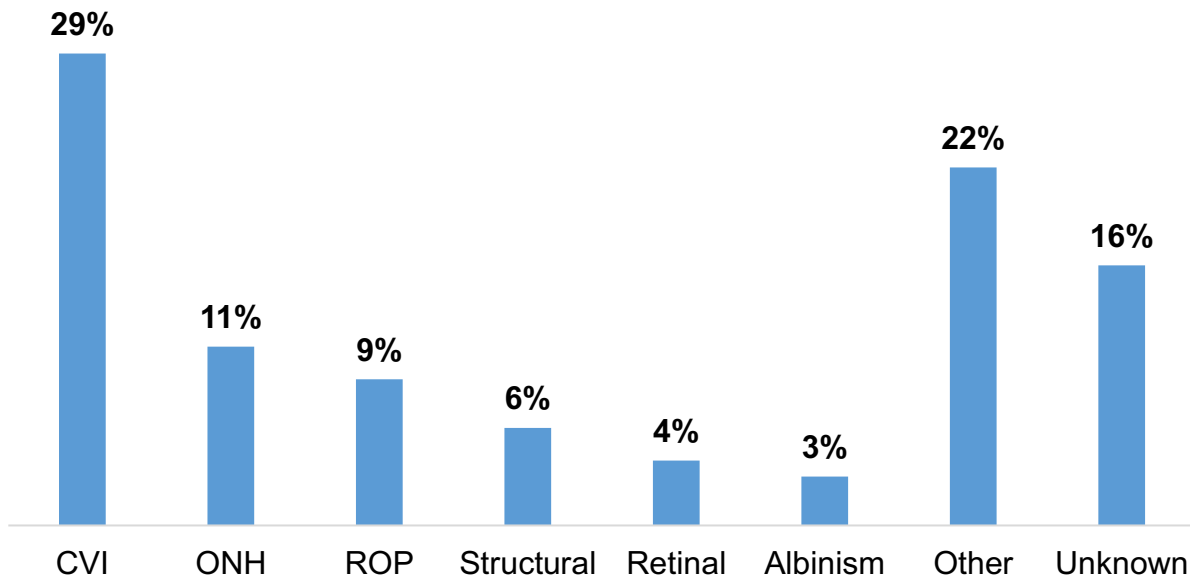
Full term = 332
37 to 33 weeks = 129
32 to 28 weeks = 44
Less than 28 weeks = 53
Total = 558
Unreported = 30

Multiple births



Single = 557
 Twins = 30
 Triplets = 1
 Total = 588

Primary Visual Condition: Both eyes

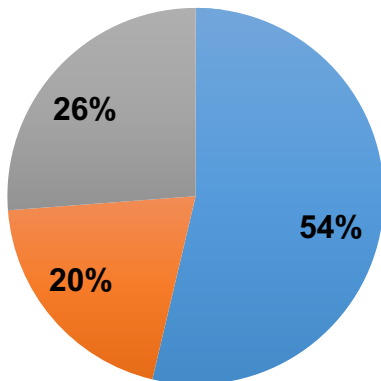


CVI = 171 Cortical Visual Impairment
 ONH = 64 Optic Nerve Hypoplasia
 ROP = 50 Retinopathy of Prematurity
 Structural = 38 (aniridia, microphthalmia/anophthalmia, coloboma, corneal disorders, Goldenhar syndrome)
 Retinal Disorders = 24 (Leber's congenital amaurosis (LCA), retinoblastoma, familial exudative vitreoretinopathy (FEVR), other retinal conditions)
 Albinism = 18
 Other = 132 (nyctagmus, strabismus, cataracts, glaucoma, ocular motor apraxia, optic atrophy, PHPV, hemianopia, nerve palsy/ptosis, choroidal hemangioma, anisocoria, and high refraction)
 Unknown/undiagnosed = 91

Additional Eye Conditions

	Right Eye		Left Eye	
	n	%	n	%
Secondary Visual Diagnosis				
None	302	51.4%	321	54.6%
Refractive error	88	15%	80	13.6%
Nystagmus	87	14.8%	86	14.6%
Strabismus	78	13.3%	72	12.2%
Amblyopia	37	6.3%	20	3.4%
CVI	23	3.9%	23	3.9%
Optic Atrophy	22	3.7%	20	3.4%
Ptosis	14	2.4%	15	2.6%
Cataracts	8	1.4%	9	1.5%
Colobomas	7	1.2%	5	0.9%
Glaucoma	6	1%	5	0.9%
OMA	4	0.7%	3	0.5%
Microphthalmia	3	0.5%	5	0.9%
PHPV	2	0.3%	1	0.2%
Hemianopia	2	0.3%	3	0.5%
ROP	2	0.3%	2	0.3%
Retinal disorder	1	0.2%	1	0.2%
Corneal disorder	1	0.2%	-	-
Vitreous hemorrhage	1	0.2%	1	0.2%
total	688	-	672	-
Number of Secondary Visual Diagnosis				
None	302	51.4%	321	54.6%
One additional	218	37.1%	205	34.9%
Two additional	47	7.0%	45	7.6%
Three or more	21	3.5%	17	2.9%

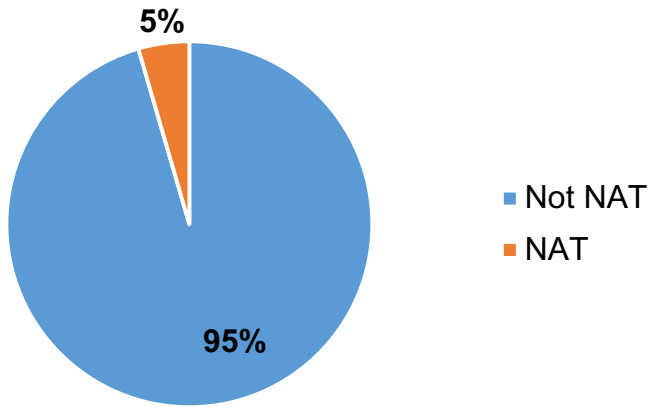
Occurrence of etiology



- Prenatal
- Perinatal
- Postnatal

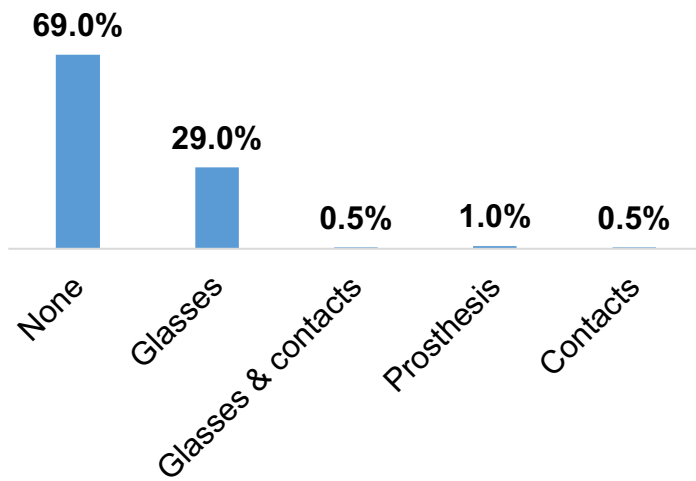
Prenatal = 232
 Perinatal = 87
 Postnatal = 113
 Total = 432
 Unreported/unknown = 156

Non-accidental trauma (NAT)



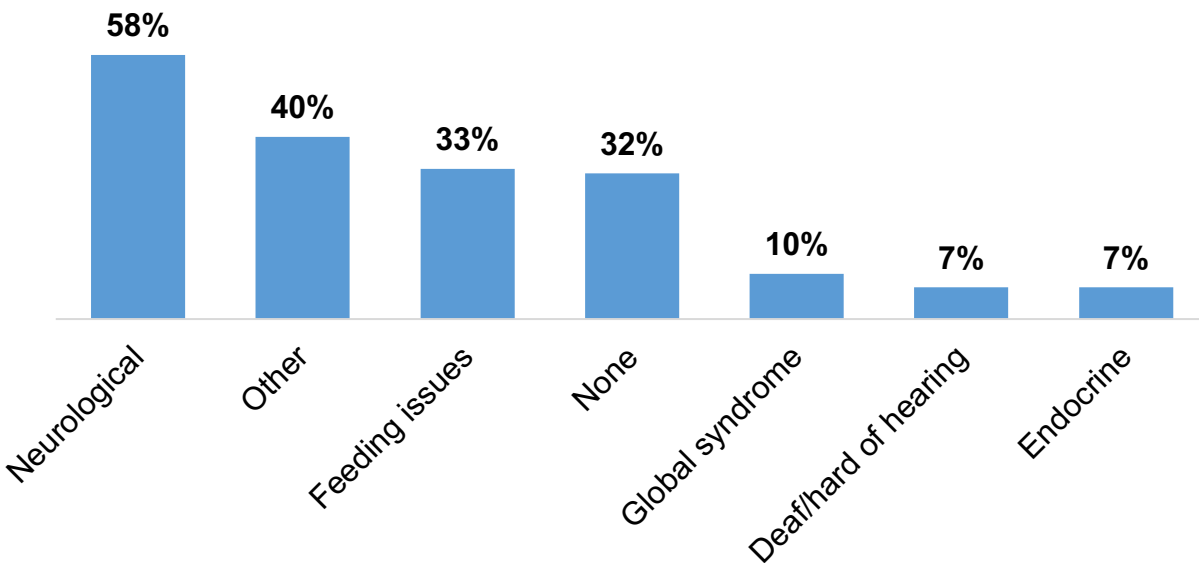
Not an NAT = 555
 NAT = 26
 Total = 581
 Unreported/unknown = 7

Use of visual optics



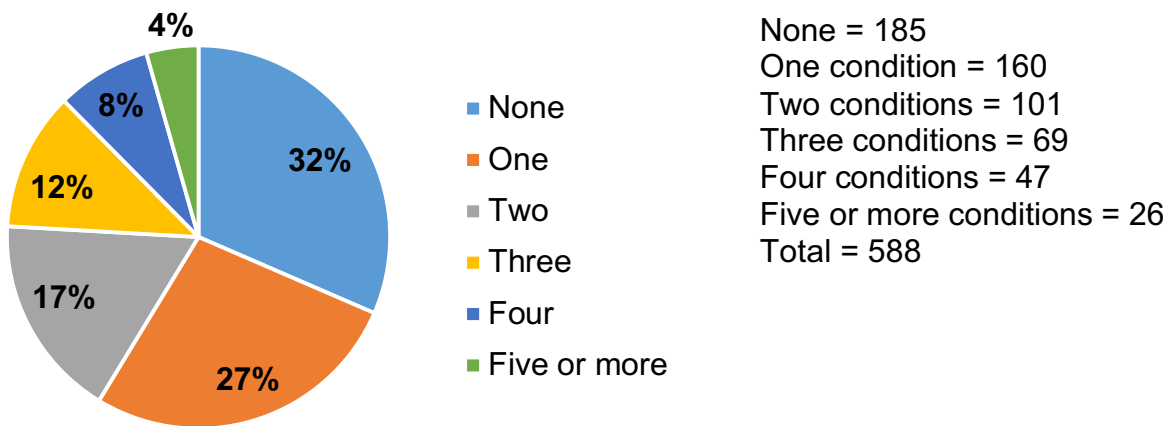
None = 408
 Glasses alone = 170
 Prosthesis = 4
 Both glasses and contacts = 3
 Contacts alone = 3
 Total = 588

Additional medical conditions

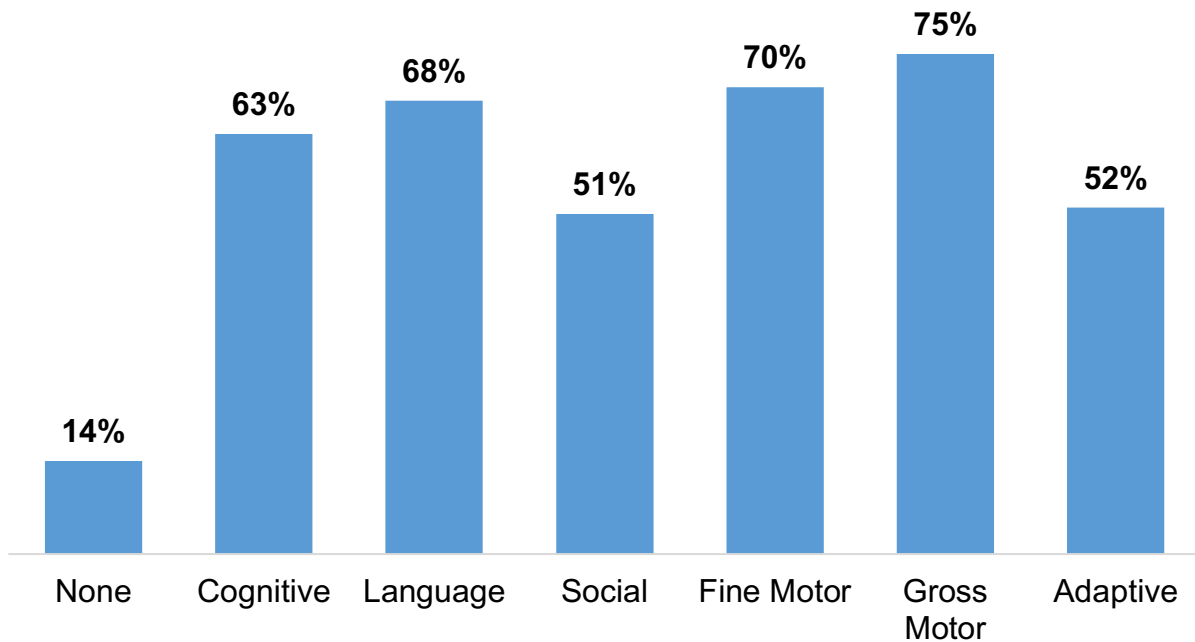


Neurological = 338 (cerebral palsy/orthopedic impairment, seizures, congenital or acquired brain disorder, Autism Spectrum Disorder (ASD), spina bifida)
 Other = 234 (cancer, technology dependent, heart condition, sleep issues, reflux/GERD, born with addiction, respiratory problems, allergies, viral sepsis infection)
 Feeding Issues = 193
 None = 185
 Global syndromes = 57 (chromosomal, mitochondrial, hereditary, genetic, cranio-facial, metabolic disorders)
 Deaf/hard of hearing = 43
 Endocrine disorder = 38

Number of additional medical conditions



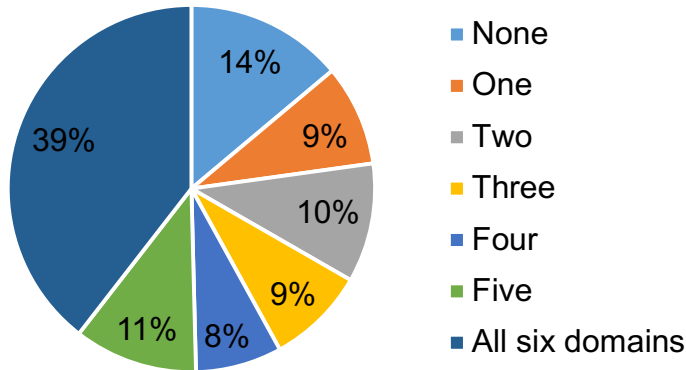
Presence of developmental delays



Developmental delays were reported individually or non-concurrently.
 None = 82 total sample had no additional developmental delays concurrent with visual impairment.

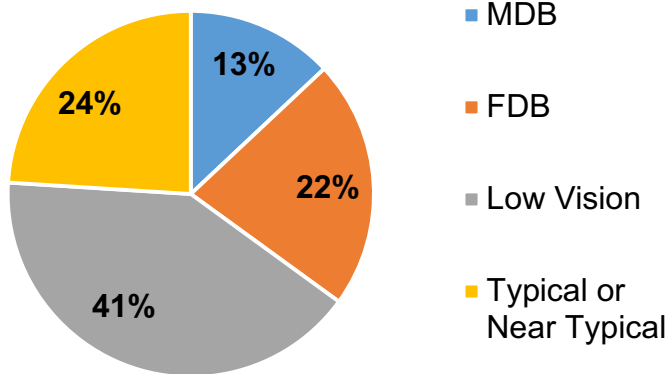
- Cognition = 368
- Language = 399
- Social = 302
- Fine Motor = 414
- Gross Motor = 438
- Adaptive = 306

Number of developmental delays



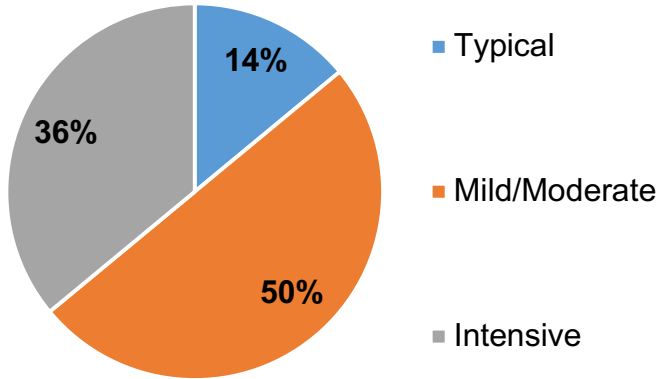
- None = 82
- One domain = 52
- Two domains = 62
- Three domains = 51
- Four domains = 45
- Five domains = 64
- All six domains = 232
- Total = 588

Level of functional vision



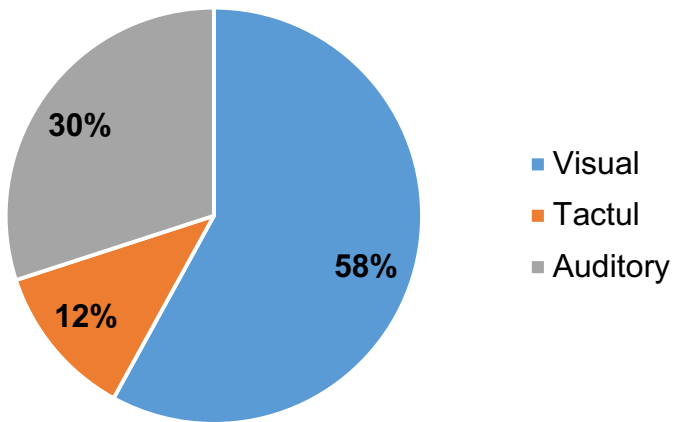
- Low vision = 241
- Typical or near typical vision = 142
- Functions at the definition of blindness (FDB) = 127
- Meets the definition of blindness (MDB) = 78
- Total = 588

Level of support needs



Mild/moderate support needs = 294
Intensive support needs = 213
Typical support needs = 81
Total = 588

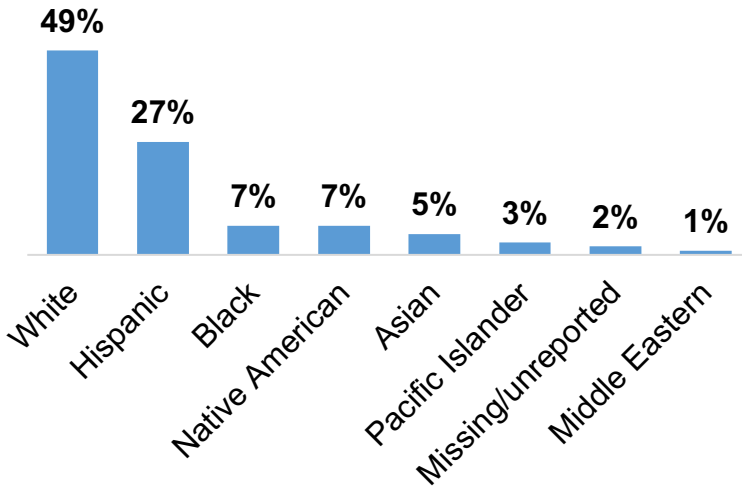
Primary learning channel



Visual = 274
Auditory = 144
Unknown/unreported = 113
Tactical = 57
Total = 588

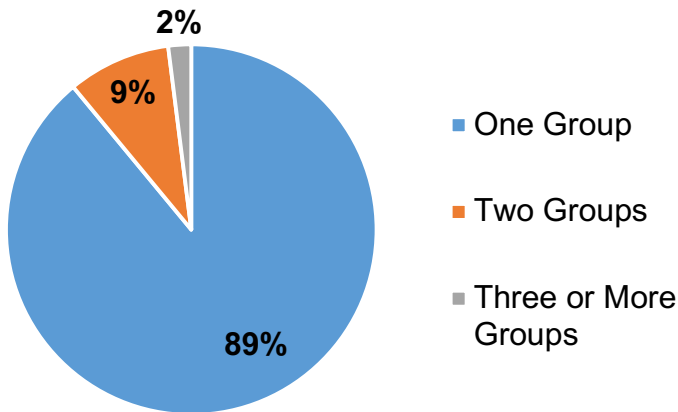
Family Characteristics:

Ethnicity



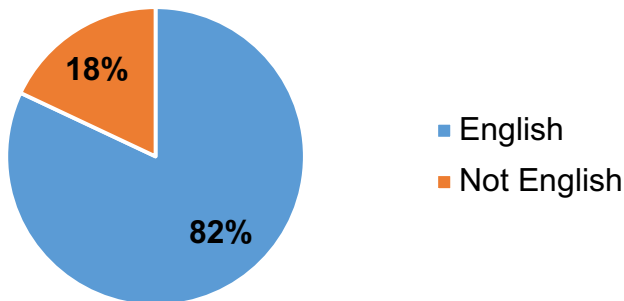
White = 325
 Hispanic = 181
 Black = 49
 Native American = 45
 Asian = 32
 Pacific Islander = 19
 Missing/unreported = 11
 Middle Eastern = 5
 Total = 667

Multiple Ethnic Makeup of Child



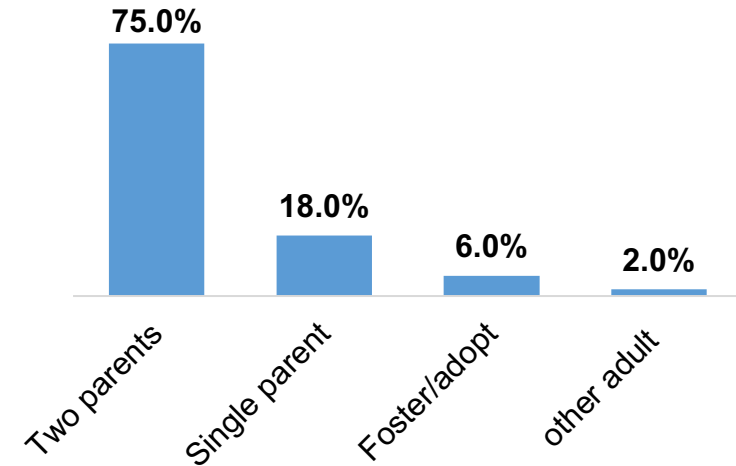
One group = 512
 Two groups = 54
 Three or more = 11
 Missing/unreported = 11
 Total = 588

Primary language



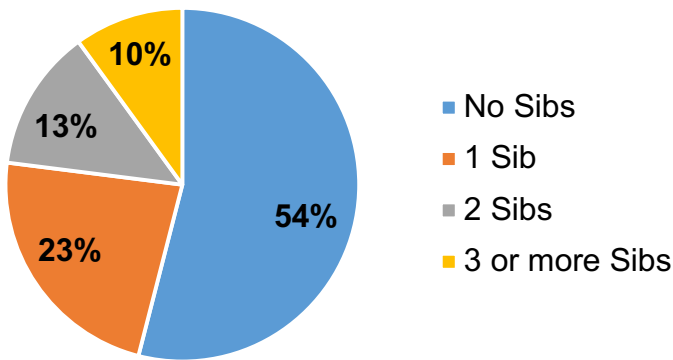
English = 478
 Not English = 108
 Missing/unreported = 2
 Total = 588

Child caregiver(s)



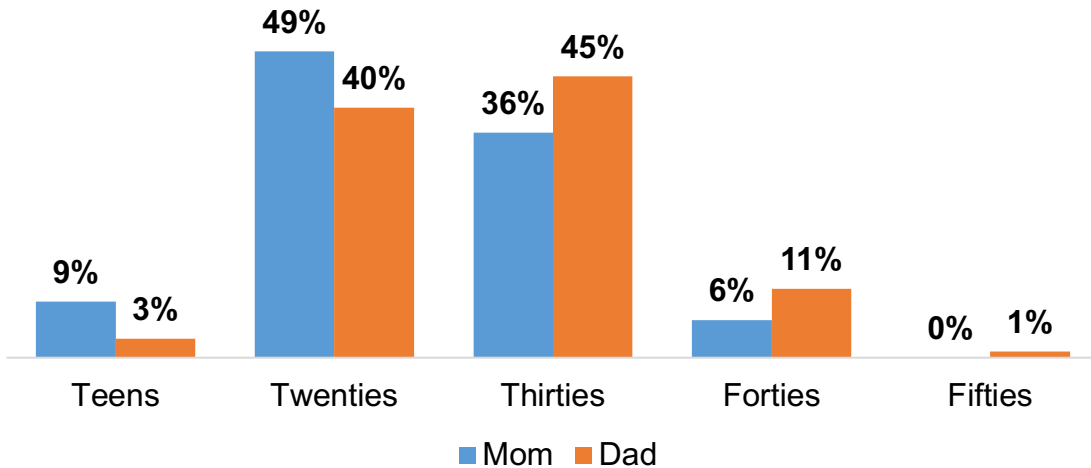
Two biological parents = 435
 Single biological parent = 105
 Foster/adoptive parent = 35
 Other adult = 12
 Missing/unreported = 1
 Total = 588

Siblings



No siblings = 316
 One sibling = 137
 Two siblings = 78
 Three or more siblings = 57
 Total = 588

Age of Biological mother and father at the birth of child



Age of Mother

15-19 years = 38
20-29 years = 198
30-39 years = 144
40-46 years = 23
Missing/unreported = 185
Total = 588

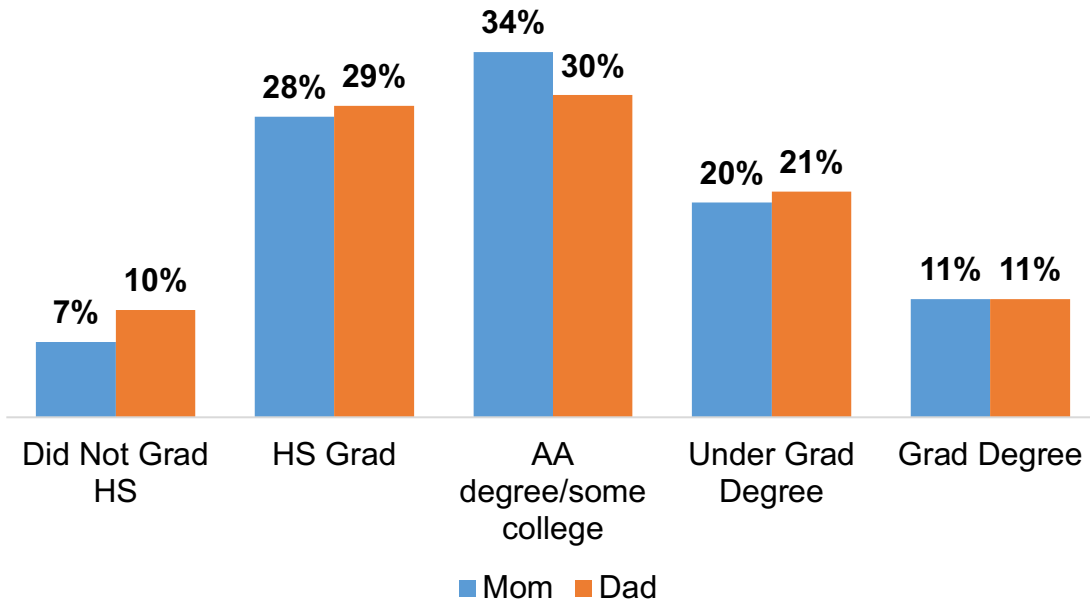
Average age = 28.3 years
Youngest = 15
Oldest = 46

Age of Father

16-19 years = 12
20-29 years = 140
30-39 years = 157
40-49 years = 38
50-56 = 2
Missing/unreported = 239
Total = 588

Average age = 31.2 years
Youngest = 16
Oldest = 56

Level of education for mother and father



Mother's level of education

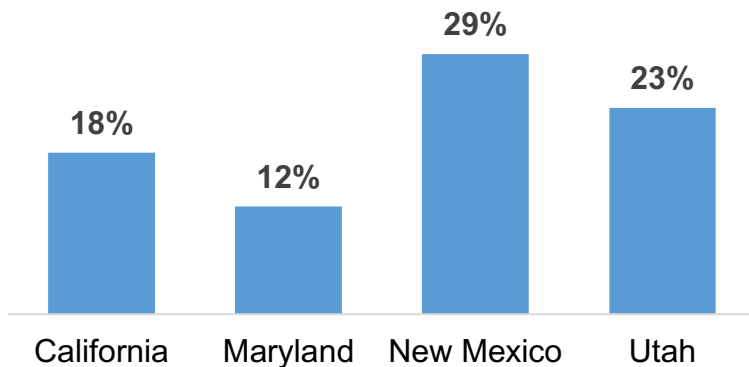
Did not graduate HS = 32
High school graduate = 122
Associate's degree or some college = 151
Undergraduate degree = 89
Graduate degree = 49
Missing/unreported = 145
Total = 588

Father's level of education

Did not graduate HS = 37
High school graduate = 114
Associate's degree or some college = 116
Undergraduate degree = 80
Graduate degree = 42
Missing/unreported = 199
Total = 588

Service Characteristics:

State



California = 104
Maryland = 70
New Mexico = 173
Utah = 136
Washington = 105
Total = 588

Age of medical diagnosis of visual impairment

- Average age of diagnosis = 7.2 months
- Variance = 42.7 months
- Standard deviation = 6.5 months
- Youngest age = 0 months
- Oldest age = 36 months
- Sample size = 502
- No diagnosis = 85 (not included in the analysis)
- Missing/unreported = 1

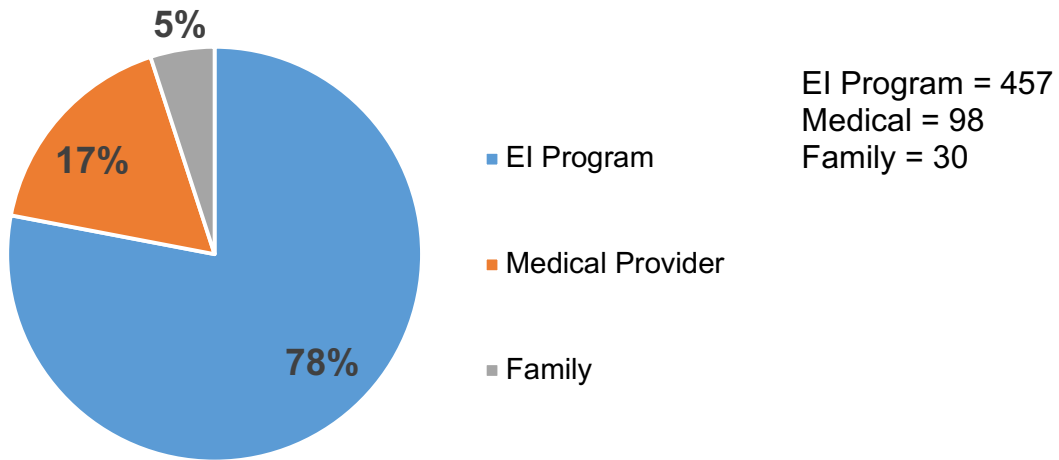
Months between diagnosis of visual impairment and referral to specialized visual impairment services

- Average months between = 5.2 months
- Variance = 33.6 months
- Standard deviation = 5.8 months
- Lowest = 0
- Highest = 26.1
- Sample size = 348
- No diagnosis = 85
- Diagnosis AFTER referral = 152
- Missing/unreported = 3

Age of referral to specialized visual impairment services

- Average age of diagnosis = 9.5 months
- Variance = 50.3 months
- Standard deviation = 7.1 months
- Youngest age = 0.2 months
- Oldest age = 33.2 months
- Sample size = 586
- Missing/unreported = 2

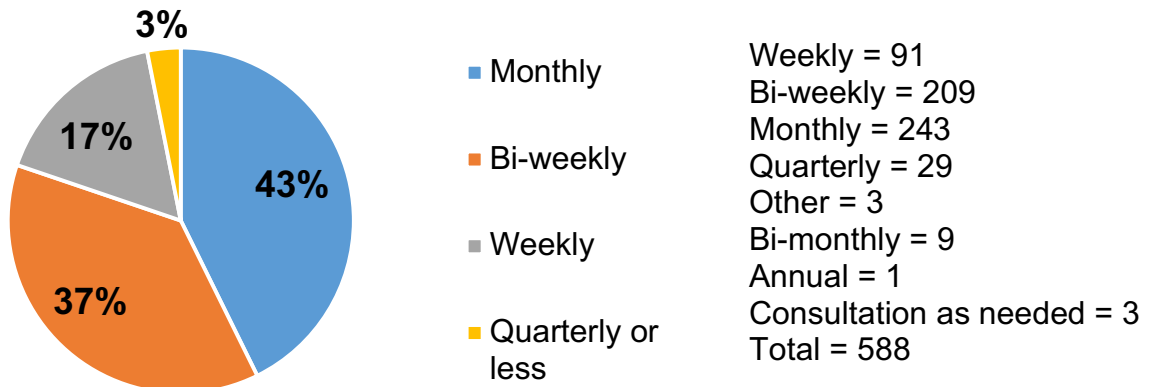
Referral source to specialized visual impairment services



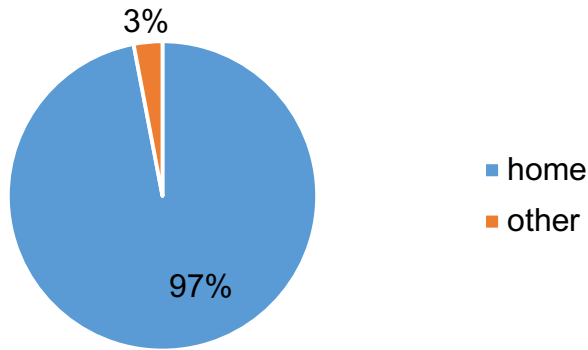
Specialized Visual impairment service provider



Frequency of specialized visual impairment service

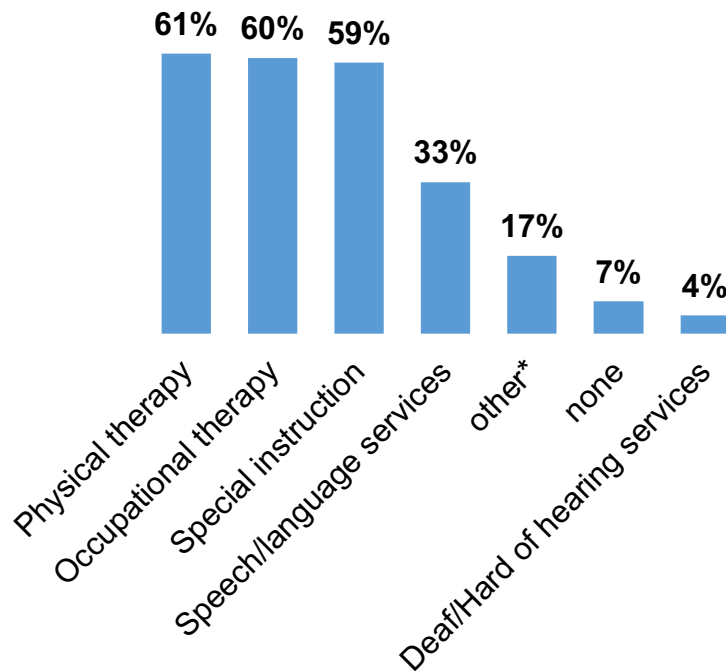


Location of specialized visual impairment service



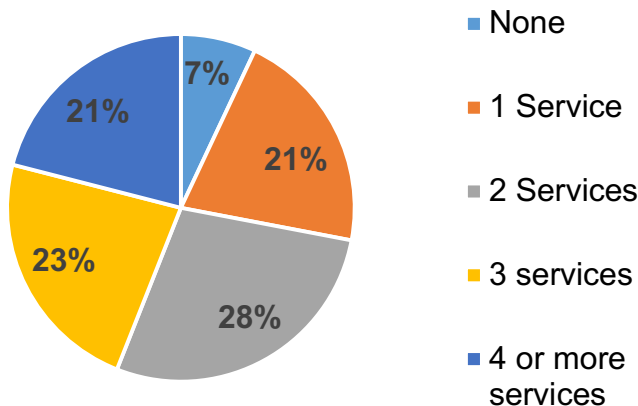
Home = 464
 Home and other = 105
 VI program/agency = 9
 Natural environment = 4
 EI center = 4
 Residential care facility = 2
 Total = 588

Early intervention services



Physical Therapy = 361
 Occupational Therapy = 354
 Special instruction = 344
 Speech/Language services = 194
 None = 42
 Deaf/Hard of hearing services = 23
 Other = 97; includes social work, nursing, other non-idea service like music therapy or hippo-therapy, feeding/nutrition, psychological, assistive technology, applied behavior analysis
 Total = 1415

Number of other early intervention services (concurrent with VI Service)



None (VI service only) = 42
 1 other service = 124
 2 services = 165
 3 services = 135
 4 or more = 122
 Total = 588